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Strategies for Delivering Sexual Health Education to Adolescents with Autism Spectrum Disorders: An Integrative Review of the Literature

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Strategies for Delivering Sexual Health Education to Adolescents with Autism Spectrum

Disorders:

An Integrative Review of the Literature

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Abstract

Autism spectrum disorder (ASD) is a neurobiological condition leading to cognitive and social deficits within individuals on the spectrum. Adolescence is a time of intense physical and psychosocial changes that proves difficult for youth with ASDs. As families work through this transition they try to navigate teaching sexual health to their adolescent with an ASD. Teaching should be done to promote health, healthy relationships, and to prevent victimization. Yet, parents report that they lack the knowledge and support to complete this task. The purpose of this literature review was to synthesize research on strategies for teaching sexual health education to adolescents with ASD. Parents are integral to this process so parental support is also reviewed. Articles were obtained from databases—CINAHL and ProQuest using the keywords: autism*, sex* education, sexual ethics, sexuality, sexual abuse, teaching methods, and technology. Studies included in the literature review were written in English, published within the last 10 years, and dealt with adolescents diagnosed with an ASD. After examining the literature, the following themes emerged: social stories as a teaching method, use of technology, support for parents, and implications for nursing. The research suggests that social stories combined with technology may be one of the most effective methods for teaching sexual health education to adolescents with ASDs. Also, healthcare providers need further education and time with families of individuals diagnosed with ASD to discuss pertinent socio-emotional and physiological aspects of sexual health. However, further research is needed on this topic.

Introduction

Background

Being diagnosed with an Autism Spectrum Disorder (ASD) is an event that fundamentally changes the ways in which adolescents and their families engage in meeting milestones throughout the adolescent's life (Halter, 2013). ASDs are defined as complex neurobiological and developmental disabilities that usually appear in a child's first three years of life (Halter, 2013). Areas of the brain that are affected disrupt the normal development of social interaction and communication skills which leads to significant deficits in social relatedness; including nonverbal behavior, and age-appropriate interactions. "Other behaviors [of ASD] include stereotypical repetitive speech, use of objects, over adherence to routines or rituals, fixations with particular objects, hyper- or hypo-reactivity to sensory input, and extreme resistance to change" (Halter, 2013, p. 192). Per the Centers for Disease Control and Prevention (2016), the prevalence of autism in the year 2000 was about 1 in 150 children, but a little over a decade later in 2012 the rate was 1 in 68 children. With an exponential increase in the rate at which ASDs are being diagnosed it is imperative that society examines best practices to assist these individuals and their families to live the best lives possible.

According to Ballan and Freyer (2017), "Adolescence is a time of great change for all youth, marked by major physical, psychological, and social transitions" (p. 262). Wrapped within this time of great change is a beginning awareness of sex and sexuality; including adolescents with ASDs. Individuals with ASD have been found to express interest and engage in sexual behaviors (Ballan & Freyer, 2017; Gilmour, Schalomon, & Smith, 2012). Yet, while adolescents with ASD enter puberty at similar times to their typically developing peers the

physical maturation is not accompanied by social and cognitive maturation (Corona, Fox, Christodulu, & Worlock, 2016).

For these reasons, we must discuss the sexual health needs of adolescents with ASDs. As discussed above, delayed social and cognitive development for individuals with ASDs influences the ways in which information can be delivered. Consequently, communication deficits create impediments when trying to gauge the depth of understanding of the material presented. One of the major concerns regarding sexual health and the ASD population is the prevalence of sexual victimization within this community. “Sexual violence victimization, sexual aggression, and sexual abuse are terms used to label being a victim of the act of coercion, use of drugs or alcohol, or the threat or use of physical force to obtain unwanted sexual contact” (Brown-Lavoie, Vecili, & Weiss, 2014, p. 2186).

Rates of sexual victimization in the ASD population are high (Brown-Lavoie et al., 2014). While the statistics are staggering, they may not represent the extent to which those in the ASD population are experiencing sexual victimization due to a gap in the research. Lehan-Mackin, Loew, Gonzalez, Tykol, & Christensen (2016) spoke with parents of children with ASD and a fear expressed by most parents was that of, “...their adolescents being sexually exploited or abused. Some parents attributed this fear to characteristics that are part of the ASD etiology such as an overly trusting nature, propensity for literal interpretations, and a willingness to please” (p. 612).

Rates of diagnosis for ASD continue to increase and rates of sexual victimization in this population are simultaneously high. While there are myriad resources for individuals and their families concerning different aspects of development for this population, resources centering on sexual education are scarce. At this point in time there are very few ASD-specific sexual health

curriculums and those that are present come with certain barriers—such as cost, access and delivery method (Lehan-Mackin et al., 2016). While issues related to communication pose barriers to the delivery of comprehensive sexual health education, this does not indicate that the education should not be provided. With a better understanding of their bodies, their sexuality, and their autonomy in decision making related to sexual contact it is the hope that adolescents with ASD would face lower rates of victimization in their lives (Brown-Lavoie et al., 2014).

One of the biggest advocates for adolescents with ASD are their parents/caregivers. For this reason, parents/caregivers are central to the successful facilitation of sexual education to their children with ASD. As Corona et al. (2016) pointed out, “providing [...] comprehensive sexuality education to adolescents with ASD is often the responsibility of parents, many of whom report that they lack the knowledge and resources needed to do so” (p. 203).

The purpose of this literature review is to use current research to examine what practices have been utilized for creating, implementing, and gauging the efficacy of comprehensive sexual health education to adolescents age 12-18 with ASD. Parents/caregivers are instrumental in the lives of their children with ASD. Thus, heavy focus will lie in examining how best to support parents/caregivers in delivering sexual health education. To engage with current practices this research will be guided by the following research questions: 1) What strategies are effective for delivering sexual health education to adolescents with ASD? And 2) What support is required for parents/caregivers to effectively teach sexual health education to their child with ASD?

Conceptual Framework

The conceptual framework used for this study is the modeling and role modeling (MRM) theory. This theory was developed in the late 1950s by Helen Erickson, Evelyn M. Tomlin, and Mary Anne P. Swain and was later published in their book *Modeling and Role Modeling: A Theory and Paradigm for Nursing* in 1983 (see Figure 1). Alligood and Tomey (2005) relate that the philosophical assumptions of the model are as follows:

Humans consist of cognitive, biophysical, social, and psychological subsystems permeated by genetic predispositions and a spiritual drive. The ongoing interaction of these multiple components creates a dynamic, holistic system that is greater than a sum of the parts. Health, which is affected by these dynamic interactions, is a perception of well-being. Although physical status influences perceptions of health, a person can perceive a high level of well-being even as he or she takes his or her last breath. Therefore, health can be defined as a dynamic, eudaemonistic sense of well-being associated with self-fulfillment and transcendence beyond objective reality of the moment. (p. 367)

With respect to this study, populations with ASD are more than the sum of their individual parts. There is a dynamic equilibrium that can and should be attained for the person to perceive their most optimal health. A part of this dynamic equation of health must be a sense of autonomy and sexual identity or expression. The MRM draws on other theories of development such as Maslow's Hierarchy of Needs, and sexual health, housed under love and belonging, is explored to transcend the levels of growth toward self-actualization.

What is most important about this concept is that it is the perception that ultimately determines the health of the individual. While biophysical, social, and psychological factors play into this perception, health is not dependent upon them. For too long the medical model of health

has dissected the human existence into disease and cure. To reach optimal levels of health all bodies are supposed to aspire to the normalized mold of health. Yet, as stated in the MRM model, health is defined by the individual. While there is no escaping the realities of our lived experiences, health can be perceived beyond objective realities of the moment. As described above, an important aspect to this picture of health includes sexual health. This liberating model is integral in the growth and development of adolescents with ASD and serves as a roadmap for any individual hoping to support them on the journey to fulfillment within their lives.

Methods

Research Design

An integrative literature review was conducted to determine current practices for teaching sex education to adolescents, age 12-18, on the autism spectrum. Additionally, the examination of best practices informed whether parents/caregivers could use these teaching methods and what support was required for them to be successful.

An integrative design was utilized to determine if there is an ideal medium for the delivery of sexual health education. According to Burns & Grove (2009), “An integrative review of research is used to identify, analyze and synthesize results from independent studies to determine the current knowledge in a particular area” (p.704). This study design was chosen due to the amount of both qualitative and quantitative data that was found within the research. Using both forms of data allowed for a more holistic understanding of the lives that adolescents are living with ASDs, the consequences that came from a lack of sexual health information, and gaps within the data that left room for further research.

A computerized search of the literature was conducted using Cumulative Index to Nursing and Health Literature (CINAHL) and ProQuest. The following key words were used to

search for relevant data: *autis**, *sex* education*, *sexual ethics*, *sexuality*, *sexual abuse*, *teaching methods*, *technology*. The results of this search are displayed in Figure 2.

Sources included for review were limited to peer-reviewed articles. Articles must be available in English. Also, articles must focus on individuals with ASDs and either their knowledge of sexual health, how sex education was delivered to them, how sexual health knowledge was measured, or how this knowledge has impacted their lives. Only full-text articles were chosen for review. All articles included within the study were published within the last ten years to maintain relevancy of the data.

Articles excluded from review were focused on disability in general, whether physical or other cognitive disabilities as this research is focused specifically on ASDs. Articles that focused on sex differences within the ASD population were also excluded as they did not contribute significant enough results to the research.

Data Synthesis & Analysis

The data collected from the articles above was ordered, categorized, and summarized into succinct results to give the reader an overview of what research is currently available (see Table 1). The data was further divided into subgroups to facilitate analysis. Critical data was extracted from each subgroup. Strategies for delivering sexual health education was pulled out from each group to verify the effectiveness and ineffectiveness of each teaching modality.

Acknowledgement of what support is needed to better facilitate education was explored to tailor the most effective strategies.

Data was combined as a group and turned into a display of variables and subgroups. Table 1. Comparison of Literature, contains sections for the source of the article, sample, age of adolescents studied, strategies, and suggestions and future directions. The data was examined to

determine patterns, themes and relationships, along with answering the original research questions posed.

Results

After an extensive review of the literature was conducted, nine studies emerged that investigated: teaching methods and their effectiveness, interviews with parents that underlined specific concerns for their adolescent along with the corresponding lack of support that they encountered, or the use of technology as an effective teaching medium in this population. Literature was reviewed by idea and key variables. Relevant themes of, social stories as an effective method for teaching aspects of sexual development, technology as a medium to conduct effective teaching, parental support or lack thereof, and the nursing implications posed by this research are further explored in discussions.

Discussion

In laying the groundwork for many of these studies published, the authors agreed on some key points that influence the findings of this paper. For example, authors agree that while adolescents with ASD show an interest and desire to engage in romantic and sexual relationships, they often receive far less education surrounding these topics than their typically developing peers (Ballan & Freyer, 2017; Corona et al., 2016). When sexual health education is provided to youth with ASD it is often found to be lacking (Ballan & Freyer, 2017; Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016; Tarnai & Wolfe, 2008).

One of the major issues related to successful teaching of sexual health education to adolescents with ASD is that there is a deficit related to social skills and social cues within this population. This aspect of development hinders understanding of the social features of sexual and romantic relationships. For these reasons, researchers have suggested that sexual education

aimed at adolescents with ASD incorporate not only the typical information from the curriculum, but also characteristics to develop greater social skills, social understanding, and social interactions (Ballan & Freyer, 2017; Barnett & Maticka-Tyndale, 2015; Corona et al., 2016; Tarnai & Wolfe, 2008). Outlined below are some of the other themes that emerged through the conducted research.

Teaching Strategies

One component of sexual health education that we tend to take for granted within our society is the knowledge that we gain through social interactions. Whether appropriate or not, we gain a good deal of our foundational and experiential knowledge about relationships and sex through our peer networks. For someone diagnosed with an ASD this social knowledge can be harder to attain. According to Tarnai and Wolfe (2008), “Lack of social skills for individuals having autism can be particularly marked in the area of intimate relationships and of sexuality” (p. 30).

One teaching strategy that has already been employed to help educate youth with ASD is the use of social stories. Social stories are a popular teaching method to demonstrate appropriate social skills and behaviors to youth diagnosed with an ASD (Ballan & Freyer, 2017; Tarnai & Wolfe, 2008). “A Social Story is a short story with specific characteristics that describes a social situation, concept, or social skill using a format that is meaningful for persons with autism spectrum disorders (Tarnai & Wolfe, 2008, p. 30). Ballan and Freyer (2017) relate to us that, “Social Stories have been associated with increased socially appropriate behaviors and decreased problem behaviors” (p. 266).

Extensive research has not been done with regards to positive outcomes associated with social stories and their use as sexual education tools. Yet, as Ballan and Freyer (2017) point out,

“Although there is little information regarding the use of Social Stories in sexuality education, it seems likely that they can be a useful tool to help individuals with ASD navigate this natural developmental transition” (p. 266).

Technology

As discussed throughout this paper, the main deficits involved in living with an ASD present as lack of communication and social skills. That is why Wainer and Ingersoll (2011) explain that, “the ASD intervention research has emphasized the development and evaluation of programs that specifically target social-communication skills” (p. 97). While figuring out which interventions will produce the best outcomes is still an ongoing task, the use technology-based programs is an intervention that is gaining a great deal of momentum (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014; Shukla-Mehta, Miller, & Callahan, 2010; Wainer & Ingersoll, 2011).

Some of the reasons that innovative technologies are being utilized in this way with the ASD population are because individuals on the spectrum have shown positive responses to the lack of social demand from a computer, the ability to have immediate and predictable responses as well as a controlled environment in which they can learn and develop (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014; Shukla-Mehta, Miller, & Callahan, 2010; Wainer & Ingersoll, 2011).

The research presented here does agree, though, that there is still a great amount of work that needs to be done around using the skills that have been learned in a simulated environment and translating that into lived experiences (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014; Shukla-Mehta, Miller, & Callahan, 2010; Wainer & Ingersoll, 2011). Advances within the technological field as it relates to ASDs gives a medium through which many different topics, including sex education, can be taught. More research and time to develop proven positive outcomes through programming is still needed.

Parent/Caregiver Support

Parents and caregivers in our society are assumed to take the role of instructor for their children when it comes to sexual health education (Ballan, 2012; Lehan-Mackin et al., 2016). Whether the school environment plays a small or a large role in sex education, parents are supposed to fill in gaps and be available for questions if needed. Even in the best situations this private education between parent and child can be marred by an unwillingness to be open and honest with one another, an awkwardness, or by a general lack of age appropriate sexually positive and accurate information.

The role of instructor is even further complicated for parents of adolescents with ASDs as the mode of information delivery must be augmented and the stakes are different when there is a lack of information presented or available. The parents in the study conducted by Lehan-Mackin et al. (2016) made multiple suggestions for effective programming that would assist parents as primary sexual educators. For example, parents suggested that technology be a medium utilized for information delivery as it could have compelling visual displays, simulation of social environments, and interactivity (Lehan-Mackin et al., 2016).

Another component that would help parents and caregivers teach sexual education to their adolescents is if they received support from healthcare providers and other staff who work with their youth's development (Ballan, 2012; Lehan-Mackin et al., 2016). As pointed out by Ballan (2012), "the majority of the parents participating in the current study indicate a strong interest and need in hearing from myriad professionals about how to better communicate with their children with ASD about issues related to sexual and reproductive health" (p. 683). This implication requires that healthcare providers be knowledgeable about the most effective ways to

deliver sexual health education to adolescents with ASD or the proper referrals to make if the situation arises.

Nursing Implications

Nurses already act as major change agents within the lives of their patients every day. That is why nurses are in the unique position to have an impact on the ASD population. Lehan-Mackin et al. (2016) point out that, “parents have an expectation that providers have some skill in the areas of disability and sexual health” and when they do not it can lead to miscommunication and a lack of perceived or actual support (p. 616). It is integral that we include all patient populations within our scope of learning and if knowledge is lacking that we seek out this information to provide the best care interventions possible.

As pointed out by McCabe and Holmes (2014), “Increasingly, clinical space is fast-paced, technology driven, task oriented and under-staffed” (p. 83). Nurses are under such demand to complete so many things that care may not always be optimal depending on the support that they receive from their institution. Yet, nurses should use best judgement around scheduling and use of physical space when caring for patients with ASDs. Having the appropriate amount of time and limiting external stimuli will improve interactions and outcomes with these patients. Controlling some of the things that can be controlled will lead to better outcomes.

One of the most important things that nurses can do for families looking for resources on teaching sexual health to their adolescent with ASD is to form relationships with local community agencies that provide services specifically targeted to this population (Lehan-Mackin et al., 2016). In this way, even if nurses are not able to provide the information themselves they are still able to ensure that patients and families are receiving the best care possible. Nurses are

thus contributing to patients with ASD building positive self-perceptions and positive images of health as outlines in the modeling and role modeling theory explained earlier within this paper.

Research Limitations

There were a number of research limitations encountered when trying to conduct this literature review. First and foremost, there is limited research conducted on this topic in general. The lack of both qualitative, but especially quantitative, data makes it hard to specify what techniques truly work to deliver this vital information. This lack of information may be compounded by the fact that teaching for adolescents with ASD is highly individualized. This makes it difficult to systematize practices for delivering sex education.

Other issues arose around the fact that there is more research done on autism, interventions and best practices, but not specifically targeted at sexual health education. This may be a product of societal norms, sex education is something that groups assume is going to be taught by someone else down the line, so this education intervention is not as researched. There is also no way to know with certainty that this research has been exhaustive.

Additionally, this research did not look at how this subject is being handled outside of the borders of the United States. It is possible that more effective measures have been utilized in other areas of the world but this was not explored within this study.

Conclusion

Individuals are being diagnosed with ASD at higher rates than ever before. It is imperative that society, especially within the healthcare society, research the most effective ways to deliver sex education to adolescents with ASD. There have been advances in technology which enables education delivery to be a multidimensional endeavor. Yet, the research is lacking

within this field of study. More comprehensive research is needed to facilitate the best possible outcomes and reduce victimization within this community.

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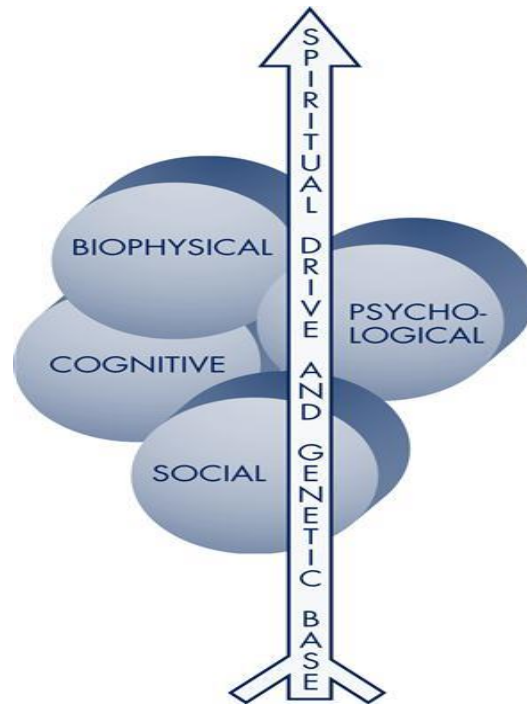


Figure 1. Relationships among the human subsystems, genetic predispositions, and spiritual drive. (From Erickson, H., Tomlin, E., & Swain, M. (1983). *Modeling and role-modeling: A theory and paradigm for nursing*. Englewood Cliffs, NJ: Appleton & Lange, with permission from Helen Erickson, Austin, TX.)

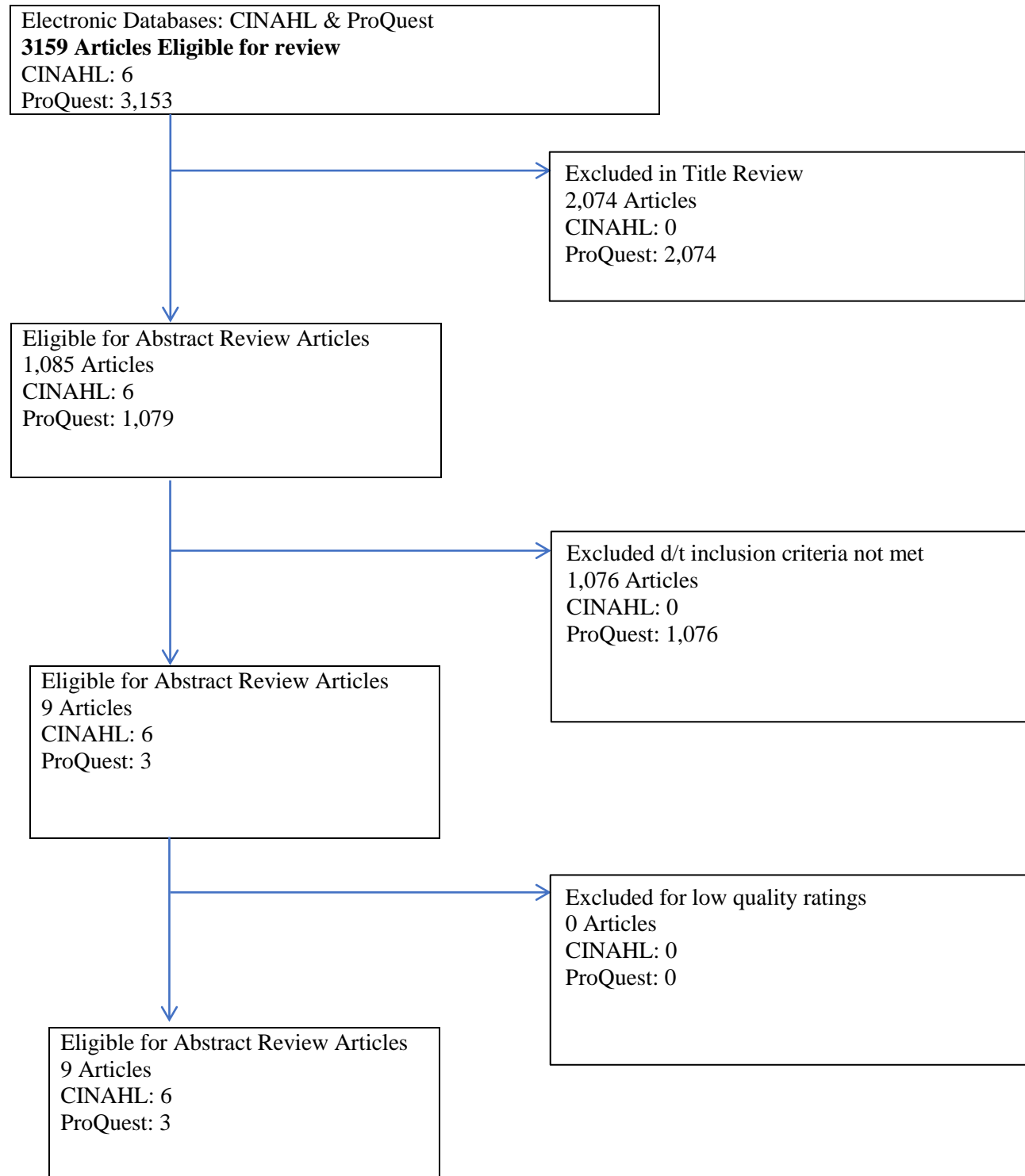
Figure 2. Diagram of Study Selection and Review Process

Table 1. Comparison of Literature

Source	Sample	Age of Youth	Strategy	Suggestions & Future Directions
Ballan, M. (2012)	18 semi-structured interviews with parents/caregivers	Parents of adolescents, aged 6-13 years old	Study shows need for targeted sexual risk reduction programs for youth with ASD. Parents express want of more info from professionals. Info delivered to youth correlated with reduced risky sexual behavior.	Majority of parents (n=16) said they would feel comfortable discussing sex but pointed to comprehension as a barrier. Some (n=6) pointed to developmental appropriateness of info. Many (n=11) wanted info from professionals.
Ballan, M., & Freyer, M. (2017)	Case report	Adolescents 11 & 12	Applied Behavior Analysis, Social Stories and Social Behavior Mapping.	There is an immense demand for resources/individuals with expertise to address socio-emotional needs of individuals with ASD. The demand outstrips the supply. Typical sexuality education programs lack the modifications necessary to be effective for youth with ASD.
Corona, L., Fox, S., Christodulu, K., & Worlock, J. (2016)	Pilot and evaluate an intervention focused on providing sexuality and relationship education to 8 adolescents with ASD and 1 parent for each child—8 parents	Adolescents between 12-16 diagnosed with an ASD	An education program separated into a parents group and an adolescents group. The material was presented in a way that was shown to be most effective for promoting learning among individuals with ASD. Pre-& posttests administered.	Individuals with ASD need additional teaching that goes beyond the classroom and uses methods that are shown to be effective with this population such as visual supports, activity schedules, and behavioral support.
Grynszpan, O., Weiss, P.L., Perez-Diaz, F., & Gal, E., (2014)	Systematic literature review yielding 22 articles	N/A	Compare research done to extrapolate best practices for use of technology and teaching individuals with ASD	The analyses showed posttest differences between groups who received technology-based intervention and teaching compared to those

				who did not. The research supports the efficacy of this type of intervention.
Hannah, L., Stagg, S. (2016)	20 neurotypically developed young adults and 20 young adults with ASDs compared sexual awareness and perceptions of adequate sex education through 2 quantitative measures followed by qualitative interviews	Young adults 18-25	Use of the <i>Sexual knowledge, experience, feelings and needs scale</i> (SexKen) and the <i>Sexual awareness questionnaire</i> (SAQ), followed by interviews	Suggestions for augmented education are offered in the form of changing the language with which education is taught. Literal interpretations of 'common' colloquialisms are pointed to as one hindrance within the classroom. While young adults with ASD reported adequate feelings of sexual awareness and sex education, their responses pointed to markedly lower results on the scales used to measure this information. This pointed to a need for more tailored information.
Holmes, L., Himle, M. (2014)	Anonymous online survey of 190 parents with child diagnosed with ASD. Groups broken up into high functioning (HF) and low functioning (LF) based on IQ score.	Parents of adolescent, aged 12-18 years old	Parents uncertain of what healthy sexuality is for their child with ASD and do not feel supported in their role to deliver this info. A need surfaced for more guidance on how & when to deliver sexuality-related topics in age-appropriate manner. Need for tailored programming for child's level of intellectual functioning, age, and unique ASD symptoms.	For HF youth, parents were least likely to endorse covering sexual activities other than intercourse (29.2 %), symptoms of STDs (27.1 %), how to use a condom (19.5 %), and how to
Lehan-Mackin, M., Lowe, N., Gonzalez, A., Tykol, H., Christensen, T. (2016)	Focus group (n=5) and telephone interviews (n=10) with parents of children with a diagnosis of ASD at any ability level	Parents of adolescents, aged 14-20 years old	Parents in this study reported a lack of material or provider resources, provider knowledge, and support for	Themes included: 1) ability to engage in relationships; 2) role responsibility; 3) child's history of sexual education; 4) fears and concerns; 5)

			issues of sexual health as they intersected with ASD. This was ultimately a barrier to parent and child communication and contributed to parent fears of “doing it wrong”.	content preferences; 6) child’s history of sexual education; and 7) recommendations for intervention development.
Shukla-Mehta, S., Miller, T., & Callahan, K. (2010)	Systematic literature review yielding 26 articles	N/A	Break up interventions by type: video modeling (VM), video self-modeling (VSM), and point-of-view video modeling (PVM)	Further research is required as method of implementation of intervention was not consistent across studies. Yet, video instruction for social and communication skills for children with ASD seems to demonstrate positive outcomes
Wainer, A. L., & Ingersoll, B. R. (2011)	Systematic literature review yielding 14 articles	N/A	Break up findings by type: language, emotion recognition, and social skills	The use of innovative computer technology is a promising strategy for delivering direct intervention to children and adults with ASD. More research is needed.